

SEPTEMBER 24

End of Life Issues (Walt Edinger, PhD)

Objectives:

1. Identify types of advance directives.
2. Describe communication strategies to increase patients' understanding of advance directives.
3. Discuss approaches to increase the use of advance directives.

SEPTEMBER 26

End of Life Issues (Dr. Eileen Baker)

PLENARY AND SMALL GROUP DISCUSSION

Objectives:

1. Describe the significance of the physician-patient relationship near the end of life.
2. Identify ethical and professional issues that commonly arise near the end of life.
3. Discuss ethical dilemmas that may arise regarding nonbeneficial medical interventions near the end of life.
4. Construct a reasoned approach to ethical dilemmas near the end of life.

Required Readings:

“Do Not Attempt Resuscitation Orders”, in: Lo, Bernard: Resolving Ethical Dilemmas, A Guide for Clinicians, pp. 136-144.

“Determination of Death”, in: Lo, Bernard: Resolving Ethical Dilemmas, A Guide for Clinicians, pp. 166-169.

“Standards for Decisions When Patients Lack Decision-Making Capacity”, in: Lo, Bernard: Resolving Ethical Dilemmas, A Guide for Clinicians, pp. 88-100.

“Beyond Advance Directives”, Tulsky JA, JAMA 2005; 294:359-65. Link: <http://0-jama.jamanetwork.com.carlson.utoledo.edu/searchresults.aspx?q=Beyond%20Advanced%20Directives&t=&p=1&s=1&c=0>

Recommended Readings:

“Physician Assisted Suicide and Active Euthanasia”, in: Lo, Bernard: Resolving Ethical Dilemmas, A Guide for Clinicians, pp. 151-161.

“Legal Rulings on Life-sustaining Interventions”, in: Lo, Bernard: Resolving Ethical Dilemmas, A Guide for Clinicians, pp. 170-178.

“Medical Futility in End-of-Life Care”, Council on Ethical and Judicial Affairs, American Medical Association, JAMA, 1999, 281:937-41. Link: <http://0-jama.jamanetwork.com.carlson.utoledo.edu/searchresults.aspx?q=Medical%20Futility%20&t=&p=1&s=1&c=0>

AMA policy :Medical Futility in End of Life Care (E-2037). <http://www.ama-assn.org/ama/pub/category/8390.html>

Assignment: (no assignment)

Case

A 78-year-old man has been treated for multiple critical conditions in the intensive care unit over the past 30 days, including sepsis, hypotension, renal failure, myocardial infarction, and ventilatory failure. Based on continuing multisystem organ failure, his treating physicians believe that further medical care has no realistic likelihood of benefit to the patient. They communicate this opinion, and recommend withdrawal of life support, in a family meeting, to the patient's wife and two sons.

The patient had no advance directive, and had not previously expressed his wishes for end of life care to any family members. The two sons agree with the physicians that withdrawal of care is appropriate. However, the patient's wife is insistent on continued care and states "I want you do to everything possible to keep him alive. My husband is a very religious man. God can save him. Don't give up on him! God can perform a miracle!"

Discussion Questions:

1. Using the "ABC Framework for Ethical Decisions", how would you evaluate and resolve this case?
 - A. Assessment: What additional information do you need to adequately assess the case scenario? Discuss the significance of various pieces of additional information, and how this would affect your perspective.
 - B. Bioethical Principles and Values: What bioethical principles and values are applicable to this case?
 - C. Capacity: Does this patient have appropriate decisional capacity? If not, who is patient's surrogate?
 - D. Decision: What courses of action should be considered? What course of action do you recommend?
 - E. Evaluation: How would you assess the outcome of the decision?
2. How can the physician balance respect for the family's religious beliefs, while presenting a realistic prognosis?
3. How can physicians balance beneficence and stewardship of health care resources in cases such as this?
4. Does the AMA policy on "Medical Futility in End of Life Care" provide guidance in cases such as this?
5. What is the significance of the physician-patient (or physician-family) relationship near the end of life?



Wednesday, August 11 2010

Opinion 2.037 - Medical Futility in End-of-Life Care

When further intervention to prolong the life of a patient becomes futile, physicians have an obligation to shift the intent of care toward comfort and closure. However, there are necessary value judgments involved in coming to the assessment of futility. These judgments must give consideration to patient or proxy assessments of worthwhile outcome. They should also take into account the physician or other provider's perception of intent in treatment, which should not be to prolong the dying process without benefit to the patient or to others with legitimate interests. They may also take into account community and institutional standards, which in turn may have used physiological or functional outcome measures. Nevertheless, conflicts between the parties may persist in determining what is futility in the particular instance. This may interrupt satisfactory decision-making and adversely affect patient care, family satisfaction, and physician-clinical team functioning. To assist in fair and satisfactory decision-making about what constitutes futile intervention: (1) All health care institutions, whether large or small, should adopt a policy on medical futility; and (2) Policies on medical futility should follow a due process approach. The following seven steps should be included in such a due process approach to declaring futility in specific cases. (a) Earnest attempts should be made in advance to deliberate over and negotiate prior understandings between patient, proxy, and physician on what constitutes futile care for the patient, and what falls within acceptable limits for the physician, family, and possibly also the institution. (b) Joint decision-making should occur between patient or proxy and physician to the maximum extent possible. (c) Attempts should be made to negotiate disagreements if they arise, and to reach resolution within all parties' acceptable limits, with the assistance of consultants as appropriate. (d) Involvement of an institutional committee such as the ethics committee should be requested if disagreements are irresolvable. (e) If the institutional review supports the patient's position and the physician remains unpersuaded, transfer of care to another physician within the institution may be arranged. (f) If the process supports the physician's position and the patient/proxy remains unpersuaded, transfer to another institution may be sought and, if done, should be supported by the transferring and receiving institution. (g) If transfer is not possible, the intervention need not be offered. (I, V)

Report: Issued June 1997 based on the report "Medical Futility in End-of-Life Care," adopted December 1996 (JAMA. 1999; 281: 937-41).

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Beyond Advance Directives

Importance of Communication Skills at the End of Life

James A. Tulsky, MD

THE PATIENT'S STORY

Mr N was a 55-year-old man with a radiographic diagnosis of pancreatic cancer invasive to colon and liver; however, biopsy was nondiagnostic. Mr N met with his primary care physician, Dr W, and told him that he wanted to pursue a tissue diagnosis and consider anticancer treatment, yet he valued his physical functioning even at the expense of longevity. He wished to avoid being "hooked up to machines" for a prolonged period but would not commit to a do-not-resuscitate (DNR) order until a diagnosis of cancer was confirmed. Mr N told his physician that he preferred to pursue this workup at another hospital because he felt his diagnosis had been missed initially at his primary care physician's facility. Mr N made all of his decisions with the assistance of his daughter, Ms N.

While awaiting further diagnostic testing, Dr W referred the patient to his hospital's Palliative Care Clinic. Mr N expressed to the palliative care team that, above all else, he wished to remain comfortable and functional. He also stated that he was forcing himself to eat and required laxatives to initiate bowel movements. One week later, the patient returned to his primary care physician complaining of fatigue, anorexia, bloating, and worsening constipation. Concerned that he might be experiencing bowel obstruction, Dr W advised surgical consultation, and the patient said he would pursue that at his local hospital. Yet, this did not happen and several days later he presented to Dr W's hospital with increasing abdominal distension and pain and was admitted to the medical service. Abdominal radiographs showed no obstruction, and he was discharged after treatment with enemas, morphine, and steroids.

Four days later, Mr N was readmitted with similar symptoms. Again without radiographic evidence of obstruction, he was treated conservatively. On the third hospital day, after no improvement, surgical consultants recommended an abdominal computed tomographic (CT) scan. When asked by his physician what he would want done if his condition should deteriorate suddenly, Mr N said that he wished to be kept comfortable but would not rule out the

Patients and their families struggle with myriad choices concerning medical treatments that frequently precede death. Advance directives have been proposed as a tool to facilitate end-of-life decision making, yet frequently fail to achieve this goal. In the context of the case of a man with metastatic cancer for whom an advance directive was unable to prevent a traumatic death, I review the challenges in creating and implementing advance directives, discuss factors that can affect clear decision making; including trust, uncertainty, emotion, hope, and the presence of multiple medical providers; and offer practical suggestions for physicians. Advance care planning remains a useful tool for approaching conversations with patients about the end of life. However, such planning should occur within a framework that emphasizes responding to patient and family emotions and focuses more on goals for care and less on specific treatments.

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possibility of surgery. He remained reluctant to agree to a DNR order. Two days later, while still awaiting the CT scan, Mr N acutely developed severe abdominal pain and x-ray showed free air under the diaphragm. With consent from the patient's daughter, he was taken emergently to surgery. The surgeon, Dr V, discovered a perforated cecum and diffuse intra-abdominal carcinomatosis. A diverting procedure was performed, his abdomen was left open, and he was discharged to the intensive care unit (ICU), intubated and hypotensive.

Dr W spoke with the patient's daughter and ex-wife who were distraught at what they saw in the ICU and who felt that the patient would not have wanted to be kept alive in this situation. They said that 10 days earlier he had com-

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pleted an advance directive to this effect. His physician advised them to obtain a copy of this document prior to making any decisions but did not specifically address code status. Shortly thereafter, Mr N experienced a cardiac arrest and resuscitation was initiated. His daughter vigorously objected and placed herself between the code team and her father. Mr N spontaneously recovered a heart rhythm, but became agitated and gestured that he wanted the endotracheal tube removed. Urgent discussions were held regarding goals of care, and the family now produced the patient's advance directive, which named the patient's daughter and ex-wife as surrogate decision makers. With their approval, Mr N was sedated, the endotracheal tube was removed, and he died shortly thereafter with his family at the bedside.

Surgical pathology confirmed the diagnosis of metastatic moderately differentiated adenocarcinoma consistent with pancreatic origin.

Mr N's daughter, Ms N, his primary care physician, Dr W, and his surgeon, Dr V, were interviewed by a Perspectives editor in December 2003.

PERSPECTIVES

Ms N (the daughter): *[A]fter the surgery, they were hooking him up to everything and they couldn't give him pain meds because . . . his heart would stop. They just kept him hanging on in agonizing pain for hours, even though I had the do-not-resuscitate document in my hand.*

Dr W (primary care physician): *In a hypothetical way, he [had] said that he would not want his life prolonged if it meant that he could not be independent and live at home and speak with his family. During his stay in the hospital, I began to talk with him in a more urgent way about what he would like done if his situation should deteriorate acutely, in particular, if he developed a perforation or a true obstruction. Would he consider surgery now? He was very reluctant to make up his mind, even after extensive discussion.*

Dr V (surgeon): *The surgical team was not fully aware of anything that was going on with his condition. After the operation was the first time I had a chance to really talk and get a feeling of what [the family] knew and what they didn't know. I told them . . . that the prognosis was not very good. [Ms N] said that . . . her dad was going to be very disappointed if he ever woke up because this aggressive care was against his wishes. I tried to hide my shock and frustration.*

Patients and their families struggle with myriad choices concerning the medical care that precedes death, ranging from the aggressiveness of treatment to the site of care. These struggles may generate conflict and dissatisfaction with the medical team.^{1,2}

Clear decision making contributes to quality of life at the end of life, and its absence may lead to worse outcomes.^{3,4} Despite a series of conversations and, ultimately, the presence of a written advance directive, Mr N, his family, and his physicians struggled with decisions about his care, ending with traumatic conflict. Confusion about goals of care

and the inability to make certain decisions meant that Mr N experienced unnecessary pain.

Even when physicians and patients try to plan for the future, advance directives are easily misunderstood or misinterpreted.⁵ This discussion reviews challenges in creating and implementing advance directives; elucidates factors that affect clear decision making, including trust, uncertainty, affect, hope, and the presence of multiple medical providers; and offers practical techniques to ease decision making at the end of life.

Advance Directives—Promising But Insufficient

Ms N: *We had decided about 2 and a half months [earlier], do not resuscitate. We had consulted with an attorney who had drawn up papers. If my father could not have good quality of life, we agreed that it was selfish to have him here in a vegetative state or in pain constantly. We discussed this over and over again.*

Advance care planning is the process by which patients, together with their families and health care practitioners, consider their values and goals and articulate preferences for future care. Written advance directives formalize these preferences and include living wills or other statements of patient preferences and durable powers of attorney for health care, which name health care proxies. Do-not-resuscitate (DNR) orders are written by physicians to operationalize one specific set of preferences articulated by patients and their proxies. Unfortunately, with few exceptions, the introduction of advance directives and the federal Patient Self-Determination Act have had little demonstrated impact on resuscitation events.⁶⁻¹³ Some of the barriers to successful implementation have been procedural when, for example, documents are not available when needed. More importantly, problems arise with deciding in advance about specific interventions,¹⁴ the adequacy of communication,¹⁵ the willingness of health care providers to follow patient preferences,^{11,16} and patient and family misunderstandings about the process.

Both procedural and communication difficulties occurred with Mr N. First, the document his daughter referred to as a DNR order was in fact an advance directive form that stated only global preferences. Mr N clearly valued quality of life over quantity of life, but his physician was unsure whether the specific instance of perforated bowel met the patient's criteria for withholding aggressive treatment.

This case is unusual in the degree of conflict between family and physicians, but it helps to illustrate that advance directives are not the same as DNR orders and generally do not provide instruction for specific circumstances. Rather, they should facilitate discussions of goals of care and consideration of all of the elements of quality at the end of life from symptom control to limitation of treatment. Because some of this care may occur after the patient has lost decision-making capacity, such discussions about advance care planning should be held with the patient, family, and physician

together to permit discussion and clarification of treatment goals specific to the patient's condition.

Decision Making Must Be Responsive to Changing Scenarios

DR W: While he was awaiting his CT scan, . . . his pressure dropped. He became unresponsive and was intubated. [After the surgery, the family was] distraught to see him in the ICU, with a tube in his mouth. They were questioning if this was what he would really want.

DR V: [T]he primary team attending came by, and I actually talked to him, as we were just about to walk out of the ER. He told me that the father didn't really want anything aggressive, but he hadn't really finished his conversation to the fullest extent. So, at that point, that was as much as I knew.

This patient's outcome, including intubation in an ICU, resulted from his stated preferences. Mr N had been unable to decide against the surgery, perhaps holding out hope that he did not have metastatic cancer or that the operation would buy him some time. When confronted emergently about whether to operate, his daughter made choices consistent with her father's expressed wishes. On the other hand, despite the patient's presumed diagnosis before surgery, the likelihood of widespread carcinomatosis and slim chance of recovery apparently was not discussed with the daughter, making the postoperative course a disturbing surprise for the family. In the emergent situation, the surgeons likely knew little about his case, but discussing with the family the possibility that Mr N would not recover from surgery and the palliative care options would have better prepared the family for the eventual outcome.

After the surgery, the prognosis was clear. Since the family did not expect the eventual outcome, and the patient could not participate in the decision-making process, a family meeting was in order to allow clinical status, prognosis, and treatment goals to be reassessed, and if necessary modified. As new information emerges, decision making must be fluid.⁷⁻¹⁹ Time-limited trials of therapy can be very useful to assess whether particular interventions are effective while defining an end to that treatment if goals are not met.²⁰ Although communication could have been substantially improved and the family better prepared, ultimately Ms N appears to have acted as her father would have in consenting to the surgery, but then wanting withdrawal of support.²¹ The tragedy occurred when the withdrawal of support was delayed, and the patient underwent an unnecessary and traumatic resuscitation attempt.

When Is a Document Needed?

DR W: [After the surgery, the family] mentioned that he had an advance directive, that a lawyer was working on it. I said that it would be really important to get that advance directive now. I went to my office, thinking I would get the fax. He went into an abnormal rhythm, and because he was still full code, . . . the MICU [medical ICU] team began resuscitation procedures.

MS N: He kept saying he was in pain, he was in pain. They called a code blue, . . . and I just started screaming, "Why won't you listen? I am giving the document that says he does not want this. He is in pain. He's talking through morphine telling you to let him die and you're ignoring his wishes."

DR W: [After the resuscitation] I had the advance directive. A no-code order was written by the MICU doctor. In one of the most horrendous experiences of my time as a physician, he kept trying to pull the tube out, saying that he was in a great deal of pain. The family decided that he didn't want the tube any more, and they decided to extubate him, which of course, was upsetting to the MICU team, which had just met him. I advised the MICU team that this was not a spur-of-the-moment decision on the part of the family or the patient. The tube was removed and he died not long after that.

Unfortunately, DNR orders are frequently not written even when this is the patient's preference.^{16,22,23} If one thing could have been done differently to change the outcome of this case (apart from providing adequate pain control), it would have been to write the DNR order much earlier—ideally before the surgery, or certainly immediately after, when the diagnosis was clear.^{24,25} Resuscitation outcomes are extremely poor in the setting of metastatic malignancy.²⁶⁻²⁸ Once the operation was completed and the patient was in the ICU, there was no reason to hold up the DNR order waiting for the advance directive document.

Written advance directives are useful when there is disagreement within a family, when there is a conflict between the family and health care team, or when the patient assigns a nontraditional family member (eg, friend or same-sex partner) as the surrogate. If the patient's preferences are known and understood by the family and team through an oral advance directive, in most states the written document is superfluous. However, to facilitate communication among members of the health care team, it is important to document the patient's preferences and how they were determined.

Key Elements of Communication

Although Mr N's physicians talked to him and his family on multiple occasions about his illness, the likely prognosis, and options for care, ultimately the patient's decisions contributed to a tragic outcome. Factors in addition to words influence how the messages of a medical encounter are interpreted and can complicate a seemingly straightforward transaction.

Trust. MS N: I think, in all honesty, that they were more interested in protecting their own jobs, not wanting to be responsible for my father's death.

Trust, the confidence that one's health care provider is acting unflinchingly in one's interest, is fundamental to effective medical care, particularly at the end of life. Ms N ascribed unprofessional motives to the physicians' actions, a belief that may have provoked her extraordinary response to the resuscitation attempt. Although conflict between provid-

Box 1. Establishing Trust With Hospitalized Patients

Taking care of patients in the hospital often requires physicians to develop relationships quickly and does not allow much time to engender trust through experience. The following may help:

Encourage Patients and Families to Talk

"Tell me what you understand about your illness."

"We've just met and there is so much going on with you right now. To help me get to know you better, can you tell me about your life outside of the hospital?"

"I'm sure that this illness has been a lot to absorb quickly. How are you coping with this?"

Do Not Contradict or Put Down Other Health Care Providers, Yet Recognize Patient Concerns

"I hear you saying that you didn't feel heard by the other doctors. I'd like to make sure that you have a chance to voice all of your concerns."

"It sounds like Dr Jones left you feeling very hopeful for a cure. I'm sure he really cares about you, and it would have been wonderful if things would have gone as well as he wished."

Acknowledge Errors

"You're absolutely right. Four days was too long to have to wait for the CT scan. Any excuses we have won't make you feel better."

Be Humble

"I really appreciate what you've shared with me about the side effects of the medication. It's clear that the approach I had suggested is not going to work for you."

Demonstrate Respect

"I am so impressed by how involved you've been with your father throughout this illness. I can tell how much you love him."

Do Not Force Decisions

"We've just had a very difficult conversation, and you and your family have a lot to think about. Let's meet again tomorrow and see how you're feeling about things then."

ers, patients, and families is not uncommon,²⁹ the establishment of trust fosters successful resolution of conflict through open and honest communication.^{2,20,29,30}

Frequently, a medical team and a hospitalized patient have not had a lengthy relationship, so physicians must rapidly create a trusting environment. In one study, women with cancer stated that feeling that a doctor cared for, understood, and respected them; gave them enough time; listened; and was open and honest encouraged them to trust physicians and accept their recommendations.³¹ Such communication can be accomplished quickly. Women who ob-

served an oncologist add 40 seconds of compassionate language to his usual encounter felt less anxious and thought the doctor cared more about the patient.³² The manner in which one interacts with a patient appears to be the most important factor to establishing trust.³³ An empathic, patient-centered style and a forum that permits an open discussion of grievances may be the best approach (BOX 1).³⁴

Uncertainty. DR W: *One of the things I learned is that presenting them with information is one thing, but assisting them in the decision making is another thing. I should have made much stronger recommendations.*

Had Mr N known for certain that he had metastatic cancer, he likely would have been inclined to accept a purely palliative approach to care and a DNR order. Had Ms N known about the likely outcome of surgery, she may have declined the intervention. However, the diagnosis and prognosis were only certain after surgery, and then she was able to make the decision to withhold further treatment.

Uncertainty characterizes all medical decision making, and physicians must help patients manage it.³⁵⁻³⁷ Surveys consistently show that most patients wish to receive as much information as possible,^{38,39} perhaps as a way to cope with uncertainty.^{36,37} However, patients who are at either extreme of preferences for decision making—those who want to be entirely in control of decisions and those who defer entirely to their physicians—are less satisfied⁴⁰ and are more anxious than those who take an intermediate role.⁴¹

This work suggests that most patients prefer to participate in decision making but wish to receive a physician's advice about recommended options. Physicians must find the balance between conveying the ambiguity that at times may cloud medical practice and helping patients find the best options for them.

On reflection, Mr N's physician believed that he could have given a clearer recommendation. Physicians tend to discuss uncertainty but frequently do not give recommendations,⁴² likely because of concerns about appearing overly paternalistic. However, such guidance is often welcome,^{39,41} particularly when based on the patient's elicited values.⁴³ In this case, the physician, aware of the patient's goals, might have advised him of the very low likelihood that certain courses of treatment would allow him to achieve these goals and could have strongly recommended a DNR order.

Affect. MS N: *It wasn't until I got emotional and started screaming and crying that anyone noticed. I don't think until then that they heard the concerns.*

Attention to affect, the feelings associated with the content of conversation, is key to resolving communication difficulties at the close of life.⁴⁴ After receiving bad news, most people are so emotionally overwhelmed that they are unable to comprehend very much about the details of the illness or treatment plan.^{45,46} Emotion affects processing; people who are in negative moods may pay more attention to the delivery than to the content of a message.^{47,48} Clinicians should attend to affect while sharing information to in-

crease the likelihood that patients will hear what they are trying to say. Unfortunately, conversations between physicians and patients often transpire only in the cognitive realm; physicians frequently miss opportunities to enter the ambit of emotions.⁴⁹⁻⁵¹

Rather than using facilitative communication techniques, such as open-ended questions or empathic responses when inquiring about psychosocial issues, studies have shown that physicians and nurses often impede discussion by changing the subject or ignoring these concerns.^{52,53} One study showed that, even in a hospice setting, only 40% of patient concerns were elicited.⁵⁴ Patients with cancer tend to disclose fewer than half of their concerns,^{53,54} leading physicians to inaccurately assess distress.⁵⁵ Communication techniques that are open-ended and focus on patients' and family members' emotional states are more likely to elicit patients' concerns about symptoms, which can then be treated (Box 2).^{56,57}

In the present case, whether the patient's or his daughter's emotions were ever acknowledged directly is unknown. It is easy to imagine that Mr N's indecision was a function of coping, at a relatively young age, with a sudden and devastating diagnosis. Similarly, his daughter was grieving terribly as she was about to lose her father and yet was distracted with worry about contacting her lawyer to get the advance directive faxed. Statements such as "Are you feeling scared?" "This must be terribly hard," or "I can't imagine what you're going through, but I'm impressed with how you've been able to cope" name and acknowledge the emotion and could have been applied effectively earlier on. They align the physician with the patient prior to engaging in the difficulties of decision making.

Hope. Virtually no one wants to die. We may be able to promise the most peaceful of final days, but 55-year-old patients rarely acquiesce to death without a fight. Hope is the frame within which they construct their future. It may be a desire for a particular outcome, or it may be, more broadly, trust or reliance. Physicians rightfully struggle to promote hope in the patient with advanced disease and to support a positive outlook.⁵⁸ Yet such an approach is frequently accompanied by an unjustified fear that discussing death may distress patients.⁵⁸⁻⁶² Physicians frequently convey overly optimistic prognoses or do not give this information at all.⁶³ Fearing the loss of hope, patients frequently cope by expressing denial and may be unwilling to hear what is said.⁶⁴ Patients with more optimistic assessments of their own prognosis are more likely to choose aggressive therapies at the end of life.^{18,65}

Physicians should recognize that it is not their job to "correct" the patient's hope for a miracle.⁶⁶ The key question is whether this hope is interfering with appropriate planning and behavior. Clinicians, at their best, can provide an empathic, reflective presence that will help patients marshal and draw strength from their existing resources (Box 3). Together, the physician and the patient can "hope for the best but prepare for the worst."⁶⁷ Helping the patient and family

Box 2. Attending to Patient Affect

Conversations about end-of-life treatment issues are emotionally charged, and it is hard for patients and families to make these decisions without first processing some of the accompanying emotions. Health care providers can assist the decision-making process by consciously attending and responding to the affect that arises during these discussions.

Acknowledge the Emotion

"Is talking about these issues difficult for you?"

"Making these decisions on your father's behalf is not easy. I wonder if it sometimes feels overwhelming?"

Identify Loss

"I bet it's hard to imagine life without your father—I can see how close you are to him."

Legitimize the Feelings

"It's quite common for someone in your situation to have a hard time making these decisions—it can feel like quite an enormous responsibility."

"Of course, talking about this makes you feel sad—it wouldn't be normal if it didn't."

Offer Support

"No matter what the road holds ahead, I'm going to be there with you."

Explore

"You just mentioned feeling scared. Can you tell me more about what scares you most?"

manage their hope and their resources in a realistic way may leave the family in the best possible shape after their loss.

Communication Among Multiple Providers

MS N: *I think that if the doctors who were working in the ICU and the emergency department had more communication with the palliative care team that would have been better because we had discussed over and over again my father's wish for a good quality of life. It kind of goes null and void when you have a whole new set of doctors who . . . just come in and start treating the patient.*

DR V: *Most times in surgery, unless we are specifically, explicitly told not to go ahead and give the most care to keep somebody alive, that's what we do. Since I was so late to this situation, I didn't know enough to step back and say, "What are we doing?" When I talked to another doctor who had seen the patient about 2 weeks earlier, he said that they had the discussions with the family, but they were never completed. This could have been prevented. His suffering could have been prevented. The terrible taste in everyone's mouth could have been prevented.*

Sharing medical information and coordinating care by multiple physicians can be challenging. Working collaboratively to honor a patient's preferences is even more diffi-

Box 3. Communicating With Hope

Talking about treatment choices at the end of life does not necessarily rob patients of hope. Redirecting the patient's goal toward realistic hopes and being present with compassion can serve as powerful acts in helping patients make decisions while maintaining a hopeful outlook. The following phrases may help:

Hope for the Best But Prepare for the Worst

"Have you thought about what might happen if things don't go as you wish? Sometimes having a plan that prepares you for the worst makes it easier to focus on what you hope for most."

Reframe Hope

"I know you are hoping that your disease will be cured. Are there other things that you want to focus on?"

"I wish, too, that this disease would just stay in remission. If we can not make that happen, what other shorter-term goals might we work toward?"

Focus on the Positive

"We've been talking about some treatments that are really not going to be effective and that we don't recommend you use. But there are a lot of things we can still do to help you—let's focus on those."

"What sorts of things are left undone for you? Let's talk about how we might be able to make these happen."

cult when providers become involved only late in the illness and during emergencies. Collaboration requires clear, consistent, physician-to-physician communication. Chart notes should include lucid discussions about patient preferences and goals for care, and, during critical illness, regular family meetings with the entire care team.^{68,69} It is useful to begin such meetings with a statement such as, "Over the past couple of days, a lot of doctors have been involved with your (or your loved one's) care. Tell me what others have been telling you about the illness."

Although the burden of maintaining continuity in our health care system ought not fall on patients and families, physicians can suggest that they keep notes from meetings with their physicians, share these with subsequent clinicians, and request that physicians communicate with each other to increase the likelihood that preferences will be honored.

From a systems perspective, electronic medical records provide a potential solution.⁷⁰ For example, the Veterans Health Administration electronic medical record system allows placement of clinical warnings that link to progress notes, DNR orders, and scanned advance directive documents. Another successful intervention is the Physician Order for Life Sustaining Treatment (POLST), a preprinted and signed physician's order specifying treatment instructions in the event of serious illness, including cardiopulmonary resuscitation, lev-

els of medical intervention, antibiotics, intravenous fluids, and feeding tubes.^{71,72} Used for community-dwelling frail elderly persons and those living in nursing homes, care has been consistent with the form in more than 80% of cases studied,^{71,72} and their specificity yields greater success at achieving palliative care goals than do advance directives.

CONCLUSION

This case is an extreme example of what can go wrong when advance care planning takes the form of nonspecific discussions and documentation as opposed to directed discussion with the physician about the patient's condition and facts of the case. Misunderstandings remain about the role and applicability of advance directive documents, and interpretation of preferences may be difficult when overshadowed by questions of uncertainty, trust, affect, and hope. Physicians can learn from this experience to not take all preferences at face value or as being static and to find ways to explore the complexities that underlie decision making. Choices can be offered in the form of recommendations that do not strip patients of their autonomy.

Advance care planning, in its broadest sense, is an important tool for physicians and their patients. However, such planning should occur within a framework that recognizes the emotions inherent in such significant decisions and focuses more on goals and less on directing specific treatments. In this sense, we must go beyond advance directives to truly meet the needs of patients making difficult decisions.

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Other Sources: For a list of relevant Web sites, see the article on the JAMA Web site at <http://www.jama.com>.

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OTHER RESOURCES

American Academy of Hospice and Palliative Medicine

<http://www.aahpm.org>

Palliative care physician membership organization provides conferences and other tools to assist health care providers communicating with patients at the end of life.

American Academy on Physician and Patient

<http://www.physicianpatient.org>

This society, devoted to the enhancement of physician-patient communication, hosts an annual course on communication skills training.

End of Life/Palliative Education Resource Center (EPERC)

<http://www.eperc.mcw.edu>

Online site with peer-reviewed educational resources, including materials on communication and end-of-life decision making.

Growth House Inc

<http://www.growthhouse.org>

Online information clearinghouse for all information related to end-of-life care.

OncoTalk

<http://www.oncotalk.info>

National Cancer Institute supported biannual retreat for oncology fellows to improve communication skills at the end of life.

Center for Palliative Care

<http://www.va.gov/durham/palliative/palliative.asp>

Research and education devoted to physician-patient communication and end-of-life care provides research and teaching resources.

The Center for Palliative Care Education

<http://depts.washington.edu/pallcare>

Well-organized compendium of educational resources with a particular focus on caring for patients with AIDS.

Discussion Guide for Facilitators:

1. Encourage the students to explore various possibilities of case development as they work through the “ABC Framework”.
2. Encourage the students to develop and demonstrate respect for religious beliefs of patients and families.

OCTOBER 3

Stewardship of Health Care Resources, Managed Care (*Dr. Catherine Marco*)

PLENARY AND SMALL GROUP DISCUSSION

Objectives:

1. Describe the principle of justice as applied to stewardship of health care resources.
2. Identify ramifications of the high rates of uninsured patients in the United States.
3. Compare proposed solutions to the high rates of uninsured patients, and their advantages and disadvantages.
4. Discuss ethical dilemmas related to stewardship of health care resources.
5. Formulate a coherent approach to the appropriate stewardship of health care resources.

Required Readings:

“Bedside Rationing of Health Care”, in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, pp. 219-226.

“The Ethics of Health Care Reform: Impact on Emergency Medicine”, Marco, et al: *Academic Emergency Medicine* 2012; 19:461-468

“Seven Provocative Principles for Health Care Reform”, Naylor, C., Naylor, K., *JAMA* 2012: vol. 307:9, pp. 919-20: <http://0-jama.jamanetwork.com.carlson.utoledo.edu/searchresults.aspx?q=Seven%20Provocative%20Principles&t=&p=1&s=1&c=0>

Recommended Readings:

“Incentives for Physicians to increase services” in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, pp. 227-229

“Measures to Control Healthcare Costs”, in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, pp. 230-237

“Global Health Equity”, Farmer PE et al: *The Lancet*, 2004; 363:1832.

Assignment: (no assignment)

SPECIAL CONTRIBUTION

The Ethics of Health Care Reform: Impact on Emergency Medicine

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Abstract

The recent enactment of the Patient Protection and Affordable Care Act (ACA) of 2010, and the ongoing debate over reform of the U.S. health care system, raise numerous important ethical issues. This article reviews basic provisions of the ACA; examines underlying moral and policy issues in the U.S. health care reform debate; and addresses health care reform's likely effects on access to care, emergency department (ED) crowding, and end-of-life care. The article concludes with several suggested actions that emergency physicians (EPs) should take to contribute to the success of health care reform in America.

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BASIC PROVISIONS OF THE PATIENT PROTECTION AND AFFORDABLE CARE ACT (ACA) OF 2010, P.L. 111-148/152

The Patient Protection and Affordable Care Act (ACA) is a federal statute signed into law along with its amendment, the Health Care and Education Reconciliation Act, by President Obama in March 2010.¹ It is designed to take effect in stages over 8 years. The ACA contains multiple provisions designed to increase access to health insurance, including expanding Medicaid eligibility, subsidizing health insurance premiums, and providing incentives for businesses to provide

health care benefits. It encourages states to create health insurance exchanges where uninsured adults and small businesses can buy insurance from a range of private insurers. Large businesses will have to pay penalties for their employees who receive subsidized health insurance in insurance exchanges, but businesses are not required to provide insurance for their employees. Most individuals, however, will be required to purchase health insurance, and this individual mandate for insurance purchase is the subject of a major challenge to the constitutionality of the ACA. To protect access to health insurance, the ACA also imposes a number of new requirements on health insurers. Insurance companies will be prohibited from denying coverage due to preexisting conditions, from dropping coverage when clients become ill, from imposing annual or lifetime limits on insurance payments, and from charging deductibles for most preventive care. The ACA also requires insurers to extend coverage for children up to the age of 26 years under their parents' insurance, even if the children do not live with their parents and are not dependents.

The Congressional Budget Office (CBO) has estimated that, after all the provisions of the ACA are in effect in 2019, the number of people with health insurance will have increased by 32 million over 2010 levels. This is a significant increase in health insurance coverage, but it does not achieve the goal of universal health insurance coverage for U.S. residents. Twenty-three million people will remain uncovered, including undocumented immigrants and those who choose not to purchase health insurance. People who would be paying greater than 8% of their household incomes on health insurance will be exempt from the requirement to purchase insurance. According to CBO estimates, the ACA will

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raise the percentage of nonelderly U.S. citizens and legal residents with health insurance from 83% to 94%.²

The extended health insurance benefits of the ACA are funded in a variety of ways, including reductions in Medicare provider reimbursements, increased Medicare taxes on higher-income Americans, new taxes on pharmaceutical and health care device manufacturers, and an excise tax on high-value health insurance benefits. To keep health insurance affordable, the ACA also includes a variety of provisions designed to curb the steadily rising costs of U.S. health care. Among its most significant cost containment provisions are the following: 1) The ACA created a Patient-Centered Outcomes Research Institute (PCORI) to conduct and fund comparative effectiveness research.³ The new information generated by PCORI should help physicians and patients choose the best available treatment options and so avoid unnecessary spending on less effective treatments. 2) The ACA establishes an incentive program for providers to form accountable care organizations, a new type of integrated health care delivery system designed to provide comprehensive care for patients at reduced costs.⁴ 3) The ACA creates the Medicare Independent Payment Advisory Board (IPAB).⁵ Beginning in 2013, the IPAB will annually recommend to Congress specific measures to keep Medicare spending within predetermined limits.

The ACA is widely acknowledged as the most significant piece of health care legislation since the establishment of Medicare and Medicaid almost a half-century ago.^{6,7} Perhaps because it is such a sweeping overhaul of the U.S. health insurance system, Congressional debate over the ACA was both protracted and highly contentious. The election in November 2010 of many staunch opponents of the ACA has made it very clear that the national debate over health care reform will continue and that full implementation of the ACA is far from assured.⁸

MORAL FOUNDATIONS OF HEALTH CARE REFORM

One way to analyze the ongoing health care reform debate is to identify basic goals of the health care system and consider how reform measures serve those goals. We contend that four fundamental goals and desires have shaped the U.S. health care system.^{9,10} First, Americans desire high (or perhaps even the highest) quality care. The reason for this desire is obvious—excellent care can provide the greatest health benefits. The goal of quality care is thus linked with the basic bioethical principle of beneficence that directs health care professionals to act for the benefit of their patients. For at least the past century, the United States has been a world leader in expanding the frontiers of medicine and improving the quality of health care. Second, Americans desire freedom of choice in health care.^{11–13} Americans want to decide when and where they receive care, what kind of care they get, and from whom they get care. The goal of freedom of choice thus reflects the basic bioethical principle of respect for autonomy that enjoins health care professionals to honor the choices of their patients. Third, Americans

want their health care to be affordable.^{14,15} If individual Americans, and U.S. public officials, spend too much on health care, insufficient resources will remain for all of the other things they need or want. Fourth, Americans want their fellow citizens to share in the considerable benefits of health care.¹⁶ Americans are unwilling to deny health care to persons in need, and the United States has established public health insurance programs to provide care to, among others, the elderly and the indigent. The goals of affordability and universal access to care raise questions of resource allocation, namely, who should enjoy the benefits of health care and who should bear the burdens of financing the U.S. health care system. Answers to these allocation questions may appeal to a variety of ethical principles of distributive justice.

We believe that these four general health system goals are all attractive and are very widely endorsed in the United States (and elsewhere). With the rapid and relentless growth of the U.S. health care system over the past half-century, however, it has become increasingly clear that these four fundamental goals are not fully compatible—that is, they cannot all be maximized at once. So, satisfaction of one or more of the goals must be compromised to achieve the others, but Americans still resent and resist such compromises. If these four health system goals are in fact so widely embraced, observers might question why U.S. policymakers cannot seem to agree on how to structure and finance a health care system that provides a limited but acceptable level of support for each goal. The probable reason for this struggle to reach agreement is that, beneath the widespread (and perhaps rather superficial) agreement on general health system goals lie significant differences in the relative priority Americans assign to the spectrum of different goals.

Consider, for example, the fact that nearly all of the world's other highly industrialized nations, including the nations of western Europe, Canada, Japan, and Australia, have health care systems that provide universal access to care for their citizens at a per capita cost significantly lower than in the United States. Citizens of these societies typically accept significant responsibility for the material welfare of their fellow citizens, often expressed in continental Europe as a principle of solidarity.¹⁷ These nations clearly place a high priority on the egalitarian goal of universal access to health care. To finance their health care systems, these nations impose a variety of constraints on other goals. For example, Germany and Japan require all citizens to obtain health insurance and all employers to contribute to insurance costs. Canada prohibits the provision of private insurance for services covered by provincial health insurance plans. The U.K.'s National Health Service restricts the adoption of high-cost therapeutic innovations, thereby limiting access to potentially beneficial new treatments. To keep health care affordable, these nations also generally impose limits on provider fees and on drug prices.¹⁸

Are Americans also willing to accept limits on health care quality and choice to finance much wider access to health care? Appeals to compassion and mutual assistance support the ACA provisions extending

health insurance to an additional 32 million people.¹⁹ Support for the ACA's expansion of health insurance can also be found in arguments for a human right to health care and for access to health care based on fair equality of opportunity.^{20,21} However, these appeals do not enjoy a clear priority in the minds of many Americans over competing claims based on individual liberty, individual responsibility, and free enterprise, values that are also deeply rooted in the American tradition. A serious constitutional challenge to the ACA, for example, is grounded on claims for individual liberty—it asserts that Americans may not be legally required to purchase health insurance. If the ACA individual mandate to purchase health insurance is overturned by the courts, and if many young and healthy Americans then choose not to insure themselves, insurers may not be able to spread their risks and costs across a large enough pool of subscribers to provide affordable coverage for the millions of new enrollees, and the entire reformed system may collapse.²² The ACA's deference to the free enterprise system is evident in the prominent role given to private health insurance companies in the reformed system, and in the defeat of a public health insurance option to compete with private insurers in newly established health insurance exchanges.²³

In summary, Americans desire a great deal from their health care system—more, in fact, than it can deliver. Because individuals hold different views about which goals should take priority in cases of conflict, compromise solutions for health care reform are difficult to achieve.

Whether or not the reforms of the ACA withstand the strong political challenges mounted against them, we believe that effective cost containment will be the most difficult problem for the U.S. health care system in the foreseeable future. Currently, the United States is

the world's highest spender on health care per capita.²⁴ Americans enjoy many benefits from higher spending, including shorter wait times for procedures, easier access to primary and specialty care, and more advanced diagnostic and therapeutic technologies and pharmaceutical agents when compared to many other countries. Ideally, Americans would like to see cost containment without reduction of services or quality.^{25,26} The strong professional and public backlash against managed care cost containment strategies in the 1990s was directed against perceived erosion of access to and quality of care. The subsequent retreat from tightly managed care, however, brought with it a return to steep annual increases in health care spending in the new millennium. An important challenge for the sustainability of the ACA, therefore, will be its ability to control health care spending.

AMERICAN COLLEGE OF EMERGENCY PHYSICIANS CODE OF ETHICS AS A GUIDING DOCUMENT

For guidance regarding the ethical dimensions of the health care reform debate, emergency physicians (EPs) might first consult foundational statements like the "Principles of Ethics for Emergency Physicians" of the American College of Emergency Physicians (ACEP;²⁷ Table 1). The "fundamental moral responsibilities of EPs" expressed in these principles lend support to the basic goals of the health care system described in Table 1 (Table 2).

Goal One: Quality Care

Principle 1 states that EPs shall embrace patient welfare as their primary professional responsibility. Principle 8 enjoins EPs to pursue continuing education to provide high-quality care.

Table 1
ACEP Principles of Ethics for Emergency Physicians

The basic professional obligation of beneficent service to humanity is expressed in various physicians' oaths and codes of ethics. In addition to this general obligation, emergency physicians accept specific ethical obligations that arise out of the special features of emergency medical practice. The principles listed below express fundamental moral responsibilities of emergency physicians.

Emergency physicians shall:

1. Embrace patient welfare as their primary professional responsibility.
2. Respond promptly and expertly, without prejudice or partiality, to the need for emergency medical care.
3. Respect the rights and strive to protect the best interests of their patients, particularly the most vulnerable and those unable to make treatment choices due to diminished decision-making capacity.
4. Communicate truthfully with patients and secure their informed consent for treatment, unless the urgency of the patient's condition demands an immediate response.
5. Respect patient privacy and disclose confidential information only with consent of the patient or when required by an overriding duty such as the duty to protect others or to obey the law.
6. Deal fairly and honestly with colleagues and take appropriate action to protect patients from health care providers who are impaired or incompetent or who engage in fraud or deception.
7. Work cooperatively with others who care for, and about, emergency patients.
8. Engage in continuing study to maintain the knowledge and skills necessary to provide high-quality care for emergency patients.
9. Act as responsible stewards of the health care resources entrusted to them.
10. Support societal efforts to improve public health and safety, reduce the effects of injury and illness, and secure access to emergency and other basic health care for all.

Table 2
Basic Goals of Health Care: Alignment with the ACEP Principles of Ethics for Emergency Physicians

Goal of Health Care		ACEP's Principle of Ethics
Quality care	1	EPs shall embrace patient welfare as their primary professional responsibility. EPs shall respect the rights and strive to protect the best interests of their patients, particularly the most vulnerable and those unable to make treatment choices due to diminished decision-making capacity. EPs shall communicate truthfully with patients and secure their informed consent for treatment, unless the urgency of the patient's condition demands an immediate response.
Freedom of choice	3,4	
Affordability	9	EPs shall act as responsible stewards of the health care resources entrusted to them. EPs shall respond promptly and expertly, without prejudice or partiality, to the need for emergency medical care. EPs shall support societal efforts to improve public health and safety, reduce the effects of injury and illness, and secure access to emergency and other basic health care for all.
Universal access to care	2,10	

ACEP = American College of Emergency Physicians.

Goal Two: Freedom of Choice

Principles 3 and 4 require EPs to respect patient rights, including the right to informed consent that gives patients substantial control over their own treatment.

Goal Three: Affordability

Principle 9 calls on EPs to act as responsible stewards of health care resources, thus recognizing the importance of conserving resources to keep health care affordable.

Goal Four: Universal Access to Care

Principle 2 calls on EPs to provide emergency care for all who need it. Principle 10 endorses the goal of access to basic health care for all.

This endorsement of all four of the basic goals of health care systems reinforces our claim that these goals are fundamental and widely embraced. The Principles of Ethics remain very general, however, because the ACEP statement does not rank these principles or consider conflicts among them. Further, it does not provide clear guidance about how to resolve conflicts based on appeals to different principles.

The ACEP Principles of Ethics do, however, offer at least two valuable suggestions. First, they endorse the goal of universal access to basic care. This concept of basic care suggests inevitable limits on the goals of quality and individual choice to achieve the goals of equity and affordability. Precisely what constitutes basic care is an important point of debate that has not yet been resolved on a national level. Second, the ACEP principles explicitly endorse the role of EPs as "responsible stewards of the health care resources entrusted to them." This is also a clear recognition of the conclusion that claims to health care resources cannot be unlimited and that EPs must play a role in setting appropriate limits. Note, however, that this stewardship role may pose ethical dilemmas for EPs who also embrace patient welfare as their primary responsibility.²⁸

In a recent commentary, Brody²⁹ offers a promising suggestion regarding how physicians can contribute to reducing unnecessary health care spending. Brody

proposes that each medical specialty society identify a "top five list" of "diagnostic tests or treatments that are very commonly ordered by members of that specialty, that are among the most expensive services provided, and that have been shown by the currently available evidence not to provide any meaningful benefit to at least some major categories of patients for whom they are commonly ordered." Brody then suggests, "each specialty society should come up with an implementation plan for educating its members as quickly as possible to discourage the use of the listed tests or treatments for specified categories of patients." Brody's proposal offers one way for physicians to become more responsible stewards of health care resources. It is our recommendation that emergency medicine (EM) as a specialty should rise to Brody's challenge to create and disseminate a "top five list" for EM.

Even after the passage of the ACA, much of the hard work of balancing the specific claims of the four basic health care system goals remains to be done. This work should be guided by moral principles, but it also requires good empirical information about treatment outcomes and costs and an effective political process.

IMPACT OF THE ACA ON EMERGENCY MEDICINE: ACCESS TO CARE AND HOSPITAL CROWDING

ED Trends

Guaranteed access to health care is currently available in the United States in only one setting, the hospital emergency department (ED). The federal Emergency Medical Treatment and Active Labor Act (EMTALA) of 1986 established an unfunded mandate to provide medical evaluation and emergent treatment for anyone presenting to an ED, regardless of his or her ability to pay. Not all visits to the ED are emergent or urgent, however. According to the recent National Ambulatory Medical Care Survey, 4.5% were triaged as needing immediate evaluation, 11.3% emergent, 38.5% urgent, 21% semiurgent (defined as needing to be seen within 1 to 2 hours or later), and 7.9% nonurgent (needing to be seen within 2 to 24 hours).³⁰

Due in part to the fact that the ED provides the only guaranteed access to health care in the United States, the number of ED visits has risen steadily over recent years to 116.8 million in 2007, an increase of 23% since 1997.²⁴ Eighty-one percent to 88% of patients currently seen in EDs have medical insurance, with a disproportionate number being covered by public insurance, such as Medicare and Medicaid plans, that have lower reimbursement rates than private insurance. The medical costs associated with treating the 12% to 19% of patients without any health insurance are largely absorbed by hospitals, as required by EMTALA. Over the two decades from 1990 to 2009, the number of hospital EDs has decreased by 27%. An increased risk of ED closure is associated with for-profit ownership, a competitive market, safety-net status, and low profit margin.³¹ These trends suggest that the burden on EDs of providing safety-net health care for uninsured patients has increased significantly over several decades.

The ACA and Access to Health Care

As noted above, the ACA will enable some 32 million U.S. citizens and legal residents to enjoy health insurance for the first time. This represents a significant addition to the estimated 254 million insured Americans.³² In theory, those who will receive first-time health insurance coverage under the ACA will no longer need to rely on EDs for routine health care and will prefer to establish therapeutic relationships with primary care physicians (PCPs). In practice, however, many of these patients may continue to present to EDs, often because they cannot find PCPs. Many PCPs will not accept these newly insured patients, because their practices are already full or because they are unwilling to accept Medicaid's low reimbursement rates. Overall, the increased number of insured Americans may be expected to improve their access to health care, which is congruent with the fourth moral foundation discussed above—that Americans want their fellow citizens to share in the considerable benefits of health care. However, the effect on already strained EDs must be considered. If many of the newly insured continue to depend on EDs as their primary source of health care, will this be a significant change from the prereform system? And, how will the expansion of health insurance coverage affect the volume and quality of ED care?

The Massachusetts health care reform experience can serve as an example of how the ACA may affect EDs and emergency medical practice. By enacting an individual mandate to purchase health insurance, Massachusetts created virtually universal health insurance for state residents in 2006.³³ Following the implementation of this statewide insurance mandate, there has been a dramatic increase in ED visits.^{34,35} Of those presenting to the ED due to inadequate access to PCPs, there was a disproportionate representation of sicker, more disabled, chronically ill, and socioeconomically disadvantaged patients. The statewide network of PCPs did not increase with increased numbers of insured patients, and one in five patients could not get in to see their physician when needed. Thus, increased access to health insurance in Massachusetts did not always

guarantee timely access to a PCP, and the ED continued to serve as a safety net provider.

Hospital crowding is an important issue with significant effects on ED operations. Crowding is a growing national problem, as EDs and inpatient hospital beds decrease and the ED population increases. An additional growing burden to EDs is the growing population of elderly patients with multiple comorbidities. If the effects of the ACA are similar to what transpired in Massachusetts, the Act may exacerbate the problem of ED crowding by an influx of many newly insured patients who have poor or no access to primary care.³⁶ Compounding the problem is lack of outpatient follow-up after ED care, which will cause these patients to return to the ED for continuing care, further exacerbating ED crowding. Although many authors have debated the costs and merits of ED visits for nonurgent conditions, EDs remain a convenient and accessible source of health care for many patients with nonurgent conditions. This aspect of ED care may continue to rise in the foreseeable future, and EPs should advocate for strategies to provide timely and appropriate care for ED patients with nonurgent conditions.³⁷

If ED crowding worsens as a result of the inability of newly insured patients to access primary care services, many EDs may be inclined to implement protocols for "deferring" or refusing ED care for nonurgent conditions. Referral of nonurgent patients to another location is already in place at some institutions. A key question is the identification of nonurgent conditions, as patients and providers often disagree about the urgency of the medical condition.³⁸⁻⁴⁰ Published studies have reached conflicting conclusions regarding whether nonurgent patients can be safely identified and refused ED care. Several early studies argued that triage criteria and predictive models are inadequate to identify patients who may be safely refused ED care.^{41,42} Three more recent studies, however, have concluded that select nonurgent patients can be safely triaged out of the ED.⁴³⁻⁴⁵ ACEP's policy on medical screening of ED patients strongly opposes deferral of care for patients presenting to the ED. ACEP believes that deferring care for patients presenting to the ED reflects a void in the health care system and recommends that in situations where patients are deferred, very specific and concrete standards be adopted by the hospital to ensure patient access to timely, appropriate treatment in an alternative setting.⁴⁶ Thus, deferral of care may have negative effects on emergency medical care, in the face of already difficult access to primary care. Furthermore, we believe that turning patients away can create moral distress for both patients and emergency providers.

Emergency medicine has been responding to primary care constraints for years, offering both acute care and preventative services. President Obama's assertion that increasing the numbers of primary care providers and providing health care insurance for nearly everyone lacking it will naturally redirect patients with minor complaints away from the ED seems questionable.⁴⁷ Early projections are for worsening of crowding in the ED, as newly insured patients seek care. In 10 years, when the positive downstream effects have a chance to catch up, there may be an easing of the total patient

flow, permitting more rapid management of the remaining acutely ill patients from triage to treatment. Unfortunately, it may prove more difficult to effect a cultural change in patients who have relied on convenient and local hospital-based ED resources for several decades. Certainly the link between insurance availability and reducing ED visits has not been convincingly made.

HEALTH CARE REFORM AND END-OF-LIFE CARE

Health care at the end of life represents a large fraction of health care expenditures in the United States. It has been estimated that end-of-life care utilizes 10% of the U.S. health care budget and 27% of the Medicare budget.⁴⁸ Improved access to care, determination and documentation of patient wishes, and following those wishes are important elements of improved cost-effective end-of-life care. Care for patients approaching the end of life is the subject of increasing attention in the U.S. health care system, as evidenced by the growth of hospice care and recognition of the new specialty of palliative medicine.^{49,50} End-of-life issues arise in the ED when patients present with end-of-life symptoms, with terminal conditions requiring palliative care, or in cardiac arrest. Over 139,000 patients die in EDs annually (0.12% of ED visits).^{24,51} Emergency care of patients near the end of life and support for family and friends present unique challenges to EPs. The ACEP policy statement "Ethical Issues at the End of Life" asserts that "Emergency physicians should respect the dying patient's needs for care, comfort, and compassion."⁵²

Many patients have strong personal preferences regarding end-of-life care. In the absence of advance directives expressing those preferences, providers and families often are unable to state the patient's end-of-life wishes accurately.⁵³⁻⁵⁵ Although advance directives can be effective communication tools when they exist, there are significant challenges to their universal application, including inaccurate public knowledge, low rates of completion, and lack of understanding of implications.^{53,54,56-58} The original ACA provision authorizing Medicare funding of advance directive discussions was written to help overcome barriers of ignorance and fear of advance care planning. This provision passed in the House of Representatives in November 2009, but was not included in the final version. Public controversy regarding the intention and potential consequences of this provision (i.e. "death panels") led to its removal from the final bill. The provision was reinserted in regulations implementing the ACA in December 2010, but was dropped once again in January 2011.⁵⁹

Critics of this provision claimed that it would permit the unbridled use of "death panels" to deny life-sustaining treatment for vulnerable patients. This claim, however, misrepresented the purpose and effects of advance care planning and of this provision. Previous studies have demonstrated that advance directive discussions are not associated with hastened death⁶⁰ and that advance directives are strongly associated with care that best meets the patient wishes, whether for life-sustaining measures or for palliative care.⁶¹ Despite its omission from the ACA, we contend that proactive

personal planning for end of life care is a valuable component of comprehensive health care reform.⁶² Funding for advance care planning consultations would enhance ethical care by helping patients to formulate and communicate their own preferences regarding end-of-life care, and helping others to understand and honor those preferences, thereby promoting patient autonomy and well-being.

ACTIONS FOR EMERGENCY PHYSICIANS

Guided by the call of the ACEP Principles of Ethics for Emergency Physicians for universal access to basic health care,²⁷ we believe that EPs should support efforts to expand access to health care in a reformed U.S. health care system. To achieve effective access to care for the millions of newly insured patients, EPs should advocate for increasing the health professional work force, including both emergency and PCPs, and expanding health care institutions, including hospitals, clinics, and urgent care centers. Along with other physicians and health care professionals, EPs must act as responsible stewards of health care resources by helping to establish and implement reasonable limits to the services they provide. In this way, EPs can contribute their unique perspective to the task of balancing the four fundamental health system goals of quality care, patient choice, affordability, and universal access.

CONCLUSIONS

Reform of the health care system will have significant influence on the practice of emergency medicine. The recently enacted Patient Protection and Affordable Care Act of 2010 has fueled, and will continue to fuel, ethical debate of several topics. This article reflects on the moral and policy issues underlying the health care reform debate, explores the likely consequences of health care reform on expanding access to health care, contributing to ED crowding and end-of-life care, and suggests actions for emergency physicians to help contribute to the success of health care reform.

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Call for Papers

The Evidence-based Diagnostics section is seeking submissions. These manuscripts will evaluate a single emergency medicine-relevant diagnosis using a systematic review and meta-analysis to summarize high quality clinical research focusing on history, physical exam, readily available lab tests, and common imaging strategies. Evidence quality will be graded using the Quality Assessment Tool for Diagnostic Accuracy Studies. The highest quality evidence will then be summarized to report point-estimates or ranges for pre-test probability, diagnostic accuracy including interval likelihood ratios, and test-treatment thresholds for definitive tests. Authors are encouraged to contact the section editor, Christopher Carpenter, MD (carpenterc@wusm.wustl.edu) with specific questions for this series.

Case 1

The ICU has only one bed open. The ED has 2 patients requiring ICU admission. One must be transferred.

Patient A: Mr. W, on the hospital board of directors, with chest pain, hemodynamically stable.

Patient B: Mr. J, homeless, alcoholic, pneumonia and respiratory failure.

The hospital CEO had previously spoken to the charge nurse and “promised” Mr. W. the last ICU bed, a cardiology consultation, and a cardiac catheterization.

Case 1 Discussion Questions:

1. What factors should be considered when determining which patient should be transferred? What factors should not be a factor in making a decision?
2. How does the principle of justice apply to this case?
3. Using the ABC Framework for ethical issues, how would you evaluate this case?
 - A. Assessment: What additional information do you need to adequately assess the case scenario? Discuss the significance of various pieces of additional information, and how this would affect your perspective.
 - B. Bioethical Principles and Values: What bioethical principles and values are applicable to this case?
 - C. Capacity: Does this patient have appropriate decisional capacity? If not, who is patient’s surrogate?
 - D. Decision: What courses of action should be considered? What course of action do you recommend?
 - E. Evaluation: How would you assess the outcome of the decision?
4. What solution do you recommend for this scenario?

Case 2

A 5 year old girl, s/p MVC, sustained severe injuries, including C-spine fracture, quadriplegia, skull fracture, liver laceration, pulmonary contusion, and others. The patient and family had no medical insurance.

The patient survived in a persistent vegetative state, ventilator-dependent, in long-term care. Medical costs exceeded \$2 million.

Case 2 Discussion Questions:

1. Is this degree of expenditure justified for a single patient?
2. Who is responsible for the medical costs?
3. Should quality of life be a consideration in determining the treatment plan?
4. Could these dollars be better spent on primary care to benefit many patients?
5. Can you recommend any systemic solutions to problems of high costs of medical care in cases such as this?

OCTOBER 4

Ethics Content (*Walter Edinger, PhD*)

- **Physician-Patient Relationship**
- **Vulnerable Populations**
- **Sexuality and the profession**

Objectives:

1. Describe significant elements impacting the physician-patient relationship.
2. Identify barriers to a successful physician-relationship.
3. Name specific patient populations that may be considered vulnerable.
4. Discriminate between appropriate and inappropriate personal relationships between physicians and patients.
5. Formulate strategies to improve vital aspects of the physician-patient relationship.

Required Readings:

“Overview of the Doctor-Patient Relationship”, in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, pp. 179-181.

“Sexual Contact between Physicians and Patients”, in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, pp. 195-200.

Assignment: Blackboard Discussion – Due October 10, 2012 before 5:00pm (1point):

Blackboard discussion: “Vulnerable populations”.

You will be placed into a small group on Blackboard.

Provide commentary on the issue.

OCTOBER 9

Ethics Content (*Walter Edinger, PhD*)

- **Conflicts of Interest**
- **Interactions with other health professionals (referral)**

Objectives:

1. Define conflict of interest.
2. Identify clinical and research scenarios that may pose a real or perceived conflict of interest.
3. Contrast appropriate and inappropriate referrals to other health professionals.
4. Discuss strategies to avoid potential conflicts of interest in the research and clinical settings.

Required Readings:

“Overview of Conflicts of Interest”, in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, pp. 213-218.

“Gifts from Drug Companies”, in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, pp. 238-42.

Assignment: (no assignment)

OCTOBER 10

Disparities in Health Care (Patricia Hogue, PhD PA-C)

PLENARY AND SMALL GROUP DISCUSSION

Objectives:

1. Identify various perspectives, values, and beliefs about health and illness among patients and health care professionals.
2. Identify issues and challenges that are important in caring for patients of different cultural backgrounds, including social, cultural, religious and personal issues.
3. Discuss contributing factors leading to disparities in medical treatment.
4. Describe the significance of individual patient communication, particularly in the context of avoiding cultural stereotypes.
5. Describe negative ramifications of discrimination and mistrust, and their effects on the physician-patient relationship.
6. Demonstrate communication and negotiation skills with patients of various cultural and ethnic backgrounds.

Required Readings:

“Ethical Issues in Cross-Cultural Care”, in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, pp. 330-338.

“Patients’ perceptions of cultural factors affecting the quality of their medical encounters”, Napoles-Springer et al, *Health Expectations* 2005; 8:4-17.

Recommended Readings:

Patient–Physician Relationships and Racial Disparities in the Quality of Health Care
| Somnath Saha et al: *Am J Public Health*. 2003;93:1713–1719

National Healthcare Disparity Report – 2008: <http://www.ahrq.gov/qual/nhdr08/nhdr08.pdf>

Office of Minority Health: <http://www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=15>

Assignment: (no assignment)

Case Discussion
Racial/Ethnic Disparities in Health Care
ROBERT PHILLIPS' STORY

Issue 1 – Disease and Illness

Robert Phillips: "I've had to curb my ambition...things I won't get to do...Imagine yourself sitting in that chair for four hours and there're parts of your body you can't move, and then you get uncomfortable towards the end of that four hours. Things start to happen to you that you can't explain, but you still can't get up. You still have to stay there...And, you know, at some point if something goes wrong, you may not make it." "I just wish medicine weren't such a bureaucracy. I just wish it felt a little more personal."

Robert Phillips gives a very detailed, personal account of what it's like to have end-stage renal disease and be on dialysis. It involves daily inconveniences, discomfort, fear, and changes in his life's goals.

- What is the distinction between "disease" and "illness?"

Issue 2 – Discrimination and racial/ethnic disparities in care

"Most of the white patients here either have had transplants or are going to have transplants. Most of the African-American patients here aren't...they're kind of in it for the long haul. Now I know there's research to back that up, a lot of quantitative research to back that up, but anecdotally it just seems like there's a big disparity...a big, big disparity."

The topic of racial and ethnic differences (disparities) in the delivery of health care services has received a great deal of attention in the last several years. Renal transplantation has been one of the areas studied.

- For what conditions or procedures have racial/ethnic disparities been documented?

Issue 3 – Stereotyping and clinical decision-making

"There is this perception that an African-American man with hypertension and diabetes is just going to ruin it anyway...which is nonsense...nonsense." (Referring to the transplanted kidney).

Whether we know it or not, we are forming stereotypes about people we meet and patients we take care of – based on race, language, style of dress, personality, etc. – all the time. It is a normal cognitive process to use limited information to make quick judgments and predictions about others. It becomes a problem when those predictions are unsubstantiated and are allowed to affect the way we interact with and make medical decisions about patients.

- What would it be like to be on the other end of a negative stereotype like this?

Issue 4 – Mistrust and communication style

"So in the African-American community, you know, Tuskegee is a big part of our experience... particularly for a generation of African-Americans; (it) has colored their behavior when it comes to medicine, right? And that generation just implicitly doesn't trust doctors. "So when I first got diagnosed and we started talking about options, he didn't really offer a lot...so I prodded him into what the options could be..."

The US Public Health Service Study in Tuskegee, Alabama of untreated syphilis was discussed briefly in the background to this story. While this study was not the sole cause of many African Americans' mistrust of science and medicine, it certainly gave credence to it. Personal experiences of discrimination, disrespect, and stereotyping, as well as documented racial/ethnic disparities in health care, also contribute to mistrust of physicians and the health care system, with good reason.

- What are the different ways you might expect patients to act when they are mistrustful?

BRIEF SYNOPSIS

Robert Philips is 29 year old African-American man who eloquently recounts his experience as an end-stage renal patient on dialysis. He developed renal failure due to focal sclerosis and after five months on dialysis he was put on the waiting list for a renal transplant. At the time of this filming he had been on the list for almost three years. He begins by describing his encounters with the health care system, and although he commends the nursing and technical staff for their services he is disappointed in the quality of physician involvement in his care. Many of his concerns revolve around the lack of supportiveness of physicians in general and of accessibility of renal transplants, particularly for African-Americans. When asked about some of the reasons for this, he attributes it to physicians not readily referring African-American patients for transplantation. He feels that he had to push his own nephrologists into giving him options besides dialysis. In his view, physicians tend to stereotype African-American dialysis patients as being less worthy of receiving kidney transplants since they're "just going to ruin it anyway."

Medical background information*

A brief discussion of end-stage renal disease, hemodialysis, and renal transplants with respect to Robert Phillips' case will be helpful for the discussion, though not the main focus. End-stage renal disease (ESRD) is the term used to describe a state of severe, permanent kidney failure generally requiring either dialysis or renal transplantation. It can be of many causes including diabetes, hypertension, glomerulonephritis, and polycystic kidney disease, among others. There are over 300,000 patients with ESRD in the U.S., many of whom are maintained on dialysis to replace the function of their kidneys—filtering the blood and maintaining the levels of various electrolytes such as sodium, potassium, and chloride. Hemodialysis, the most common form, involves a catheter inserted into an enlarged blood vessel (fistula) in the arm, which diverts arterial blood through a filtration device and back into circulation. This generally requires the patient to sit in a chair, connected to the dialysis machine, for several hours a day, three days a week. The hemodialysis itself can cause a drop in blood pressure, nausea, headaches, and dizziness, among other side effects. Over the long term, the patients suffer from more chronic problems such as severe hypertension, bone weakness, anemia, and early heart disease. The option of renal transplantation has become an excellent one for many ESRD patients, and tens of thousands have been performed worldwide. Still, the demand for donor kidneys far exceeds the supply. Transplantation, when successful, can restore most patients to a near-normal lifestyle. Many factors affect kidney survival, including strict adherence to the immunosuppressive regimen and control of other chronic diseases. There are two major sources of donor kidneys: HLA matched relatives that are willing to donate, and cadavers whose organs have been harvested through a nationally coordinated network. Advances in immunosuppressive medication, among other factors, have improved the survival of the transplanted kidneys to 13.8 years for cadaver donor kidneys, and 21.6 years for related donor kidneys. African-Americans are much less likely than whites to receive renal transplants. Studies have shown that they are referred less frequently for renal transplantation. Once referred, they wait longer on renal transplant lists, in part due to having fewer HLA matches with cadaver donor kidneys. Interestingly, recent data have shown that while matching 6 out of 6 HLA antigens is clearly superior to fewer matched antigens, the survival rates for less than perfect matches are not significantly different from each other. This has prompted changes in the transplantation policy that should reduce the disparities.

* Source: www.uptodate.com and Harrison's Principles of Internal Medicine, 15th edition

Background on African-Americans and health care disparities in the United States*

The history of African-Americans in the United States, from slavery to the present, is one of discrimination and segregation in virtually all sectors of society. In the 1800s, pseudo-scientific theories about race and the physical and mental inferiority of blacks attempted to legitimize this discrimination in a country that preached democracy and the rights of individuals. After the Civil War and emancipation, the U.S. government established the “Freedman’s Bureau” to provide assistance to former slaves, including the development of racially segregated hospitals. Segregation persisted for nearly a century under the legal protection of “Jim Crow” laws. The 1960s saw an end to legalized segregation, the passage of federal civil rights legislation, and the creation of Medicare and Medicaid. This brought about the desegregation of hospitals and healthcare systems in this country. Progress in improving African-American health in the U.S. seemed to be on the horizon, when the revelation of medical experimentation (a longstanding issue dating back to slavery) reemerged in the 1970s with an expose of the Tuskegee Syphilis Study. This study, funded by the U.S. government, was designed to follow the natural history and progression of syphilis in humans. African-Americans with this disease served as the “control group” and did not receive treatment, even after penicillin had become available and was known to be effective. This further contributed to mistrust of the healthcare system by African-Americans. Obviously, this has taken a severe toll on African-American health and perspectives on health care. Despite advances in medicine that have improved the health of the majority of Americans over the last fifty years, African-Americans have benefited much less from this progress. African-Americans suffer disproportionately from chronic, treatable conditions such as cardiovascular disease, diabetes, cancer, HIV/AIDS, and asthma, just to name a few—all culminating in a lower life expectancy. These “racial and ethnic disparities in health” are in part due to many of the usual suspects in our society—poor education, poverty, and persistent discrimination—that unfortunately plague many Americans, particularly African-Americans. But perhaps even more disturbing is what has more recently been learned about racial and ethnic disparities in the delivery of health care. A 2002 Institute of Medicine Study entitled “Unequal Treatment” found overwhelming evidence that patients were being treated differently by the health care system, based on their race and ethnicity. African-Americans and other minorities, with the same insurance and socioeconomic status as white patients, receive poorer, lower quality care for heart disease, cancer, diabetes, kidney failure, pain management, and the treatment of HIV/AIDS, just to name a few. As the nation struggles with how to deal with these glaring disparities, African-Americans struggle with their own health issues within a health care system that has continued to validate their fears and mistrust.

* Sources:

- “Unequal Treatment.” The Institute of Medicine 2002 (www.nap.org)
- Byrd WM, Clayton LA. *An American Health Dilemma. A Medical History of African Americans and the Problem of Race.* New York, NY: Routledge; 2000.

Issue 1 – Disease and Illness

Robert Phillips: "I've had to curb my ambition...things I won't get to do...Imagine yourself sitting in that chair for four hours and there're parts of your body you can't move, and then you get uncomfortable towards the end of that four hours. Things start to happen to you that you can't explain, but you still can't get up. You still have to stay there...And, you know, at some point if something goes wrong, you may not make it." "I just wish medicine weren't such a bureaucracy. I just wish it felt a little more personal."

Robert Phillips gives a very detailed, personal account of what it's like to have end-stage renal disease and be on dialysis. It involves daily inconveniences, discomfort, fear, and changes in his life's goals.

- **What is the distinction between “disease” and “illness?” – Student Discussion Question**
- What do end-stage renal disease, dialysis, and renal transplantation mean for Robert Phillips and how are these meanings likely to be different for health care professionals?
- How should physicians deal with each of these?

Health care professionals should try to understand how the patient is experiencing the illness (including cultural factors) in addition to understanding the disease.

Discuss *disease* as the medical perspective on sickness —the dysfunction of organ systems, the physical signs, expected symptoms, prognosis, etc.—basically, everything that you read in a medical textbook. *Illness*, on the other hand, is the patient's experience of being sick. Robert Phillips describes the illness of end-stage renal disease and what it's like to live with it day to day. The background section for this case describes the disease. The perspectives are very different. Medical education primarily focuses on the learning about disease, and this is often perceived to be the most important aspect of a clinician's role. But if you ask patients, this is only part of what is important to them. They value health care professionals who listen to them, understand their perspective, explain things to them, and treat them as individuals. Essentially, they value clinicians who understand the illness as they do. The way patients understand and experience an illness is, to a large extent, culturally determined. This video illustrates that Robert Phillips' illness is personal and also influenced by his experience as an African-American.

Issue 2 – Discrimination and racial/ethnic disparities in care

“Most of the white patients here either have had transplants or are going to have transplants. Most of the African-American patients here aren’t...they’re kind of in it for the long haul. Now I know there’s research to back that up, a lot of quantitative research to back that up, but anecdotally it just seems like there’s a big disparity...a big, big disparity.”

The topic of racial and ethnic differences (disparities) in the delivery of health care services has received a great deal of attention in the last several years. Renal transplantation has been one of the areas studied.

- **For what conditions or procedures have racial/ethnic disparities been documented? – Student Discussion Question**
- Why might African-Americans have to wait longer for renal transplants, and be less likely to receive them overall than whites?
- How could this affect a patient’s (such as Robert Phillips’) attitude toward doctors and the medical system?
- What could be done to improve health care delivery to racial/ethnic minorities?

Racial/ethnic disparities have been well documented for all types of health care services. Focus has shifted toward understanding the root causes and developing effective interventions. Cultural competence (defined broadly) is seen as one important intervention.

This is an opportunity to discuss the issue of racial/ethnic disparities in health care and procedures such as renal transplantation, as well as Robert Phillips’ personal experiences. Since this may lead to a heated and challenging discussion, it is particularly important to review the facts about disparities. It would be helpful to read the article by Ayanian, et al., which shows that African-Americans are less likely to be referred for renal transplantation than whites. There are several possible reasons for these disparities seen that should be discussed: 1) it is often assumed that African-American patients may be less likely to want renal transplantation. While the Ayanian study (among others) shows that there was a small difference in preference, it did not explain the magnitude of the difference in referral for transplantation. 2) Another reason could be physician bias, either conscious or unconscious. While this is a sensitive subject, numerous studies suggest that patient characteristics such as race/ethnicity and socioeconomic status do affect the way physicians perceive patients and make clinical decisions. This will be discussed more with the next issue on stereotypes. 3) There may be barriers to communication or to the doctor-patient relationship that could affect the decision to refer a patient for transplantation. 4) Finally, the organ transplantation system has been set up to favor giving organs to patients who have a higher number of HLA matches. This results in African-American patients waiting a substantially longer time for organs than white patients due to a lower rate of matches (though this should not affect physician referral patterns). While there is evidence that a complete HLA match (all 6 of 6 HLA matched) has a higher success of organ transplantation, it has not been shown that a higher degree of partial match is beneficial (i.e., 5/6 HLA matches has not been proved to be better than 3/6 HLA matches, etc.). Because of this, several organ transplantation systems are now in the process of changing their criteria.

Focus on Racial/Ethnic Disparities in Health Care

Research has uncovered striking disparities in the health care of minority patients relative to whites. The most compelling data focus on African-American patients, but a growing body of work is documenting a similar pattern of lower quality health care for Latinos and other minorities as well as non-English speaking patients. A major review of these disparities entitled “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care” was undertaken by the Institute of Medicine and released in 2002. The committee for this extensive, high-profile project was comprised of both experts in the area of disparities and also well-respected physicians with no previous research interest in this area of study who was brought in to provide a critical perspective and to assure an unbiased report. The final report documented that “Evidence of racial and ethnic disparities in healthcare is, with few exceptions, remarkably consistent across a range of illnesses and healthcare services” (IOM summary p 4). Studies show that, even when accounting for socioeconomic status and insurance, minorities are less likely than whites to:

- receive appropriate cardiac medications for coronary artery disease
- undergo cardiac catheterization
- undergo bypass surgery
- receive hemodialysis for renal failure
- be referred for renal transplantation once on dialysis
- receive pain medication for long bone fractures in the ER
- receive antiretroviral therapy for HIV
- undergo curative surgery for lung cancer

There have also been disparities found in cancer screening, pediatric care, mental health, and general medical services, among many others. Many of these disparities in care are directly linked to poorer health outcomes. Most take into account factors like insurance, income, age, and symptom expression. The emphasis in research has shifted from documenting that disparities exist to developing strategies to eliminate them. “Cultural competence” of health care providers, facilities, and the medical system itself has been proposed as one step toward eliminating disparities. Cultural competence has been defined by Lavizzo-Mourey and Mackenzie as a health care system that “acknowledges and incorporates—at all levels—the importance of culture, the assessment of cross-cultural relations, vigilance towards the dynamics that result from cultural differences, the expansion of cultural knowledge, and the adaptation of services to meet culturally unique needs.” Educational efforts for students and residents is one example. Others include legislation, research on root causes of disparities, patient education and empowerment, standardization of care, and public health efforts. Allow the students to discuss specific ideas themselves.

Issue 3 – Stereotyping and clinical decision-making

“There is this perception that an African-American man with hypertension and diabetes is just going to ruin it anyway...which is nonsense...nonsense.” (Referring to the transplanted kidney)

Whether we know it or not, we are forming stereotypes about people we meet and patients we take care of – based on race, language, style of dress, personality, etc. – all the time. It is a normal cognitive process to use limited information to make quick judgments and predictions about others. It becomes a problem when those predictions are unsubstantiated and are allowed to affect the way we interact with and make medical decisions about patients.

Discuss the stereotype that Robert Phillips is referring to and its potential effect.

- **What would it be like to be on the other end of a negative stereotype like this? – Student Discussion Question**
- How might the stereotype that Robert Phillips is referring to and its potential effect, affect a physician’s medical decision to refer a patient for a transplant?

Stereotyping is a normal cognitive process that can negatively affect clinical decision-making. Physicians should be careful of the stereotypes they may subconsciously hold, and avoid acting on false assumptions, especially about race, ethnicity, religion, gender, sexual orientation, etc.

Robert Phillips is describing the stereotype that as an African-American man, he will not take care of himself or manage his chronic medical conditions adequately, and this will cause his new kidney to fail. He feels that, rather than realizing that he is a very motivated and health conscious individual, his doctors are lumping him together with “other African-Americans” whom they stereotype as “non-compliant.” The application of stereotypes is oftentimes automatic, and most likely to be based on race, gender, and age. It is thought that given the daily information overload in the clinical setting (identification of patient signs and symptoms, knowledge of pathophysiology, choice of diagnostic and therapeutic modalities, etc.); there is an attempt to conserve cognitive resources by using stereotypes to help simplify the volume of information to which we are exposed. The inherent danger in following this process is that providers apply inappropriate group beliefs to individual patients. Perhaps the most fascinating and relevant fact about stereotypes is that individuals tend to activate them the most when stressed, multitasking, and under time pressures...the hallmarks of the environment of daily medical practice. Discuss the students’ own experiences of being stereotyped or how they imagine it would feel (**this is a good opportunity for culturally diverse students to teach their colleagues about the realities of prejudice**).

Issue 4 – Mistrust and communication style

“So in the African-American community, you know, Tuskegee is a big part of our experience... particularly for a generation of African-Americans; (it) has colored their behavior when it comes to medicine, right? And that generation just implicitly doesn’t trust doctors. “So when I first got diagnosed and we started talking about options, he didn’t really offer a lot...so I prodded him into what the options could be...”

The US Public Health Service Study in Tuskegee, Alabama of untreated syphilis was discussed briefly in the background to this story. While this study was not the sole cause of many African Americans’ mistrust of science and medicine, it certainly gave credence to it. Personal experiences of discrimination, disrespect, and stereotyping, as well as documented racial/ethnic disparities in health care, also contribute to mistrust of physicians and the health care system, with good reason.

- **What are the different ways you might expect patients to act when they are mistrustful? – Student Discussion Question.**
- What are your overall impressions about the issue of patient mistrust of physicians and medicine in general?
- In what ways could mistrust affect the ability of patients to get good health care?
- How apparent (to the physician) is this mistrust when it is present?

Mistrust of physicians and medicine may be expressed directly by patients or may remain hidden, and can lead to poor health outcomes. Physicians should be aware of mistrust, avoid taking it personally, and try to build trust with patients.

The way patients express their mistrust depends to a large degree on their style of communication. Robert Phillips has a very direct style of communication. People who are more direct may express their mistrust more openly, or even confrontationally. It is important for physicians to avoid taking this personally and to try and build trust and reassure patients of their good intentions. Mistrustful patients may question the options being offered or the decisions that have been made about their care. When their style of communication is indirect or non-confrontational, they may agree with the physician but then not follow up with treatment plans that they were skeptical about, or simply not come back. They may offer subtle clues that they are mistrustful, like mentioning a negative experience that a relative had with medical care, or the fact that they try to avoid coming to the doctor. It is important to explore these issues further with all patients, but especially when their style of communication is indirect.

Patients who are mistrustful may avoid coming to see doctors in general. They may be skeptical of preventive care, medications, tests, and operations, and thus be less likely to receive these when needed. This may be due to their own preferences, or physicians may be reluctant to offer them. Their attitude toward health care professionals may lead to difficulties in establishing relationships with them, thus leading to poor continuity of care. It is crucial to try and build trust with patients, since a personal relationship with a physician who is perceived to be caring and trustworthy will often override the general mistrust of medicine as a whole.

OCTOBER 17

Ethical Issues of Genetic Testing - Patient Panel (*C. Marco, M.D.*)

Objectives:

1. Identify advances in genetic testing and associated ethical issues.
2. Describe appropriate uses of genetic testing in clinical cases.
3. Compare contrasting viewpoints on the widespread application of genetic testing.

Recommended Readings:

“Ethical Issues in Genomic Medicine”, in: Lo, Bernard: *Resolving Ethical Dilemmas, A Guide for Clinicians*, pp. 311-320.

“Working towards ethical management of genetic testing” (Parker M et al: *The Lancet* 2002; 360:1685-88)

“Genetic epidemiology and public health: hope, hype, and future prospects” (Smith GD, Ebrahim S, Lewis S et al: *The Lancet* 2005; 366:1484-98)

“Disclosure of genetic tests for health insurance: is it ethical not to?” (Raithatha N, Smith RD: *The Lancet* 2004; 363:395-6).

“More than I wanted to know” (Hill J: *The Lancet* 2004; 363:1654).

OCTOBER 18

Ethical Issues in Genetics (*Dr. Eileen Baker*)

Objectives:

1. Identify ethical issues that influence genetic counseling.
2. Name factors that should be considered prior to prenatal genetic testing for genetic traits, gender, or disability.
3. Integrate ethical issues into a rational approach to prenatal testing and counseling.
4. Discuss the significance of confidentiality for genetic testing, including release of information to relatives, health care providers, and insurers.
5. Recommend a rational approach to genetic testing and its application in clinical medicine.

Recommended Readings:

“Preimplantation Genetic Diagnosis” (Sermon K et al: The Lancet 2004; 363:1633-41)

“Rapid and simple prenatal DNA diagnosis of down’s syndrome” (Verma L et al: The Lancet 1998; 352:9-12)

“Ethical problems before conception” (Hope T, McMillan J: The Lancet 2003; 361:2164)

“Microarray genetic screening: a prenatal roadblock for life?” (Shuster E: The Lancet 2007; 369:526-29)

OCTOBER 18

The Future of Genetic Testing: “Gattaca” (movie) (*Dr. Catherine Marco*)

Bonus Assignment: Individual Paper – Due October 25, 2012 before 5:00pm (1point):

Individual paper: “Ethical Issues of Genetic Testing”

Identify ethical issues in genetic testing. Recommend a rational approach to genetic testing and its application to clinical medicine.

Suggested length is 1-2 pages to be submitted via Blackboard Bonus Assignment drop box.

For questions contact Nick Bell.

ETHICS PROJECT

Due November 8, 2012 before 5:00pm (7 points):

A. TOPIC:

Choose any one of the following topics to address for your Ethics Project:

Principles of Bioethics

Physician-Patient Relationship

Vulnerable Populations

Disparities in Health Care

Genetics

Organ Donation

Minors: Consent and confidentiality

B. MODALITY:

Choose one of three project modalities: research paper, literature, or video.

Choose a modality that interests you and would be a good way to illustrate ethical principles related to the topic you have chosen. Be as creative as you like!

GENERAL GUIDELINES:

Research paper:

Suggested length: 4-6 pages, including 3-10 references.

Research the topic you have chosen and provide a review of the topic.

You may wish to include a case discussion as a portion of the manuscript.

Literature

Suggested length: 3-4 pages.

Select one or more relevant literature selections (book, movie, poetry) that relate to the topic you have chosen.

Read the selection(s) and provide a commentary on the literature and its relevance to the topic.

Video

Suggested length: 10-15 minutes

Create a video related to the topic you have chosen.

You may elect to enact a clinical scenario or ethical dilemma.

Include commentary on the ethical issues relevant to the topic.

Additional modalities may be acceptable upon request

(contact Dr. Marco at Catherine.Marco@utoledo.edu or 383-6343)

C. INDIVIDUAL OR GROUP:

Choose whether you prefer to work individually, or in a group (up to 4 participants).

D. DUE DATE:

You may complete and submit your project anytime up to November 8, 2012 at 5PM.

E. **GRADING CRITERIA**

The Ethics Project will be graded for a total of 6 points.

Grade will be based on:

- | | |
|--|----------|
| 1. Initiative/creativity | 1 points |
| 2. Illustration of ethical principles | 2 points |
| 3. Content – accuracy and completeness | 3 points |

TOTAL FOR FULL CREDIT

6 POINTS

Bonus point:

- | | |
|--|-----------------|
| 4. Combination of effort, content, and initiative. | 1 point (BONUS) |
|--|-----------------|

MAXIMUM TOTAL

7 POINTS

TOTAL GRADING POINTS FOR YEAR 1 ETHICS CURRICULUM PORTION OF CDM:

<u>Required Assignments:</u>	<u>Due date</u>	<u>Points</u>
Individual paper: "Principles of Bioethics"	9/5/12	2
Web CT discussion: "Vulnerable populations"	10/10/12	1
Ethics Project	11/8/12	6
Ethics Project Bonus Point		1
<u>Bonus Assignments:</u>		
Individual paper: "Patient autonomy"	9/25/12	1
Individual paper: "Ethical Issues of Genetic Testing"	10/24/12	1
Total (<i>including bonus point</i>)		12